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Attitudes towards decisions about extremely premature infants differed between Swiss linguistic regions in population-based study

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Abstract: AIM Studies have provided insights into the different attitudes and values of healthcare professionals and parents towards extreme prematurity. This study explored societal attitudes and values in Switzerland with regard to this patient group. METHODS A nationwide trilingual telephone survey was conducted in the French-, German- and Italian-speaking regions of Switzerland to explore the general population's attitudes and values with regard to extreme prematurity. Swiss residents of 18 years or older were recruited from the official telephone registry using quota sampling and a logistic regression model assessed the influence of socio-demographic factors on end-of-life decision-making. RESULTS Of the 5112 people contacted, 1210 (23.7%) participated. Of these 5% were the parents of a premature infant and 26% knew parents with a premature infant. Most participants (77.8%) highlighted their strong preference for shared decision-making, and 64.6% said that if there was dissent then the parents should have the final word. Overall, our logistic regression model showed that regional differences were the most significant factors influencing decision-making. CONCLUSION The majority of the Swiss population clearly favoured shared decision-making. The context of sociocultural demographics, especially the linguistic region in which the decision-making took place, strongly influenced attitudes towards extreme prematurity and decision-making.

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Attitudes to decisions about extremely premature infants differed between Swiss linguistic regions in population-based study

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Short title: Making decisions about extremely preterm infants

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ABSTRACT

Aim: Studies have provided insights into the different attitudes and values of healthcare professionals and parents toward extreme prematurity. This study explored societal attitudes and values in Switzerland with regard to this patient group.

Methods: A nationwide trilingual telephone survey was conducted in the French, German and Italian speaking regions of Switzerland to explore the general population's attitudes and values with regard to extreme prematurity. Swiss residents of 18 years or older were recruited from the official telephone registry using quota sampling and a logistic regression model assessed the influence of socio-demographic factors on end-of-life decision-making.

Results: Of the 5,112 people contacted, 1,210 (23.7%) participated. Of these 5% were the parents of a premature infant and 26% knew parents with a premature infant. Most participants (77.8%) highlighted their strong preference for shared decision-making and 64.6% said that if there was dissent then the parents should have the final word. Overall, our logistic regression model showed that regional differences were the most significant factors influencing decision-making.

Conclusion: The majority of the Swiss population clearly favoured shared decision-making. The context of socio-cultural demographics, especially the linguistic region in which the decision-making took place, strongly influenced attitudes toward extreme prematurity and decision-making.

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Keywords: End-of-life decision making, extreme prematurity, moral pluralism, population survey, shared decision-making

Key Notes

- A nationwide telephone survey was conducted in the French, German and Italian speaking regions of Switzerland to explore the general population's attitudes and values with regard to extreme prematurity.
- Most of the 1,210 adults (77.8%) highlighted their strong preference for shared decision-making and 64.6% said parents should have the final word in cases of dissent.
- Our logistic regression model showed that regional differences were the most significant factors influencing decision-making.

INTRODUCTION

Despite a steady increase in survival rates for infants born at the limits of viability (1,2), long-term morbidity has not decreased accordingly. Data on long-term outcome and quality of life (QoL) are essential for decision-making, but their interpretations vary largely (3-5).

This prognostic uncertainty raises various difficult ethical questions. For instance, decision-making can be influenced by the diverging attitudes and values of healthcare professionals, parents and society at large with regard to treatment options for infants born extremely premature. Diverging attitudes have led to considerable variability in clinical practice, predominantly caused by cultural differences and personal beliefs (6-8). Also, the degree of parental involvement in medical decision-making for extremely preterm infants has shown to be embedded

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in the diverging social and cultural practices in France, the United States and Canada (9,10).

A transparent discussion on attitudes and values is necessary to reconcile medical and ethical deliberations with socio-religious and personal predispositions in end-of-life (EoL) decisions. Assessing the views and values of a given society may be helpful in understanding the opinions and views put forward by parents and neonatal staff and can illustrate how disagreements about end-of-life decision-making (EoLDM) can arise.

To date, empirical data have provided limited insight into the effect of societal attitudes and values on EoLDM for infants born at the threshold of viability. Therefore, the purpose of this study was to examine the attitudes and values within the Swiss population toward extreme prematurity, in order to assess whether socio-cultural or religious-based differences would lead to diverging EoL decisions.

METHODS

Design and population

For this population-based telephone survey, the initial German questionnaire was translated into French and Italian. The translation accuracy was checked with back-translation into German and reviewed by a panel of translators to ensure identical semantic content in each language.

The questionnaire was used to assess the participant's opinions, attitudes and views regarding extremely preterm infants. Participants were informed that extremely preterm infants were those born before 28 weeks of gestation, with a birth weight of between 600 and 800 grams, who always required intensive care treatment.

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The survey consisted of 16 questions with a mean interview duration of 13.8 minutes and a 95% confidence interval (95% CI) of 13.5 to 14.0 minutes. This paper focuses on the following themes: decision-making about intensive care measures, views on intensive care measures and associations with acceptable QoL. Furthermore, demographic information was gathered on gender, age, residency, importance of religion, education and income level, personal experience with prematurity and whether the participants had children. This included whether they had premature children themselves or knew parents who had.

Data collection

The nationwide telephone survey was conducted in 2013 by the market and social research institute gfs-zurich, which recruited adults of 18 years or older living in Switzerland from the official telephone registry by means of quota sampling. Quotas were set in terms of sex, age and residential location for each linguistic region to make our sample representative of the demographic distribution of Switzerland.

As this anonymous population survey did not include any patient data or health-related data, the Ethical Committee of the Canton of Zurich did not require formal ethical approval.

Statistical analysis

Only 4% of the Swiss population live in the Italian-speaking part of the country and 200 of the 1,210 interviewees were selected from the Italian-speaking region. This enabled to obtain a larger sample to allow us to compare the three language areas. For comparisons between the groups, for example levels of education and importance of religion, the answers were weighted so that respondents from the

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Italian-speaking region accounted for 4% of the answers. The weighing process was based on the official data of the Federal Statistical Office and allowed us to get a precise sociodemographic picture of the Swiss population. For proportions, 95% CIs were calculated according to the formula devised by Wilson and reported where appropriate. Groups were compared using a chi-square test.

A logistic regression model was performed to assess the association between medical decision-making and socio-demographic factors. Factors included linguistic region, educational level, gender and strength of faith and were chosen because of their significance in a preliminary univariate analysis. Odds ratios and 95% CIs were calculated from single factors of the logit function and a p value of < 0.05 was considered statistically significant.

Weighting and analysis were conducted using IBM SPSS Statistics software, version 22 (IBM Corp, New York, USA).

RESULTS

Sample

Of the 5,112 people contacted, 1,210 completed the telephone survey, giving us a response rate of 23.7%. The main characteristics of the respondents are shown in Table 1. One in 20 of the respondents (5%) was the parent of a premature infant and 26% knew the parents of a preterm infant in their close social environment. Religious faith was stronger in the German-speaking (54.1%) and Italian-speaking region (53.3%) than in the French-speaking region (41.6%).

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Decision-making about intensive care treatment options

In terms of intensive care treatment decisions, the majority (77.8%) of the population preferred shared decisions between parents and healthcare professionals (Table 2), as the decision-making model for infants born extremely premature. Few people (2.6%) would confer the decisional authority to the ethics committee. Socio-demographic factors that had a significant effect on responses were age and linguistic region. People under 39 years of age were more likely (82.7%) to regard shared decision-making as important than older respondents of 40-64 years (75.6%) and 65 years or older (74.4%). Furthermore, giving physicians the sole authority to make decisions was higher in the Italian-speaking (10.5%) than German-speaking (2.5%) and French-speaking (2.6%) regions. The healthcare team had more authority in the Italian-speaking (8.0%) and French-speaking (6.3%) regions than the German-speaking region (2.0%).

In cases where there was dissent between the parents and the healthcare team, 64.6% stated that parents should have the final word in decision-making. Only 11.4% of the respondents specified the ethics committee as the final decision-making authority. Again, the socio-demographic factors age and linguistic area shaped the opinions on decision-making (Table 2). Compared to younger people under 40 years of age (70.0%), older people over 65 years (57.8%) were less likely to say that the parents should be the final decision-makers. In the German-speaking region, parents were more often (69.9%) designated as the final decision-makers. Respondents from the French-speaking (17.8%) and Italian-speaking areas (18.5%) gave more final power to the physician to make decisions than the German-speaking region (10.2%).

Research showed that the criteria for the initiation of intensive care treatment were often stricter for extremely preterm infants than for older children with the same prognosis for long-term outcome (11). The majority (62.6%) of participants felt the

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criteria for intensive care treatment should be the same, 17.8% said it should be stricter and 12.7% said the criteria should be less strict. Male respondents and those who were childless or very religious, advocated more liberal criteria for initiating intensive care in extremely preterm infants.

Perceptions of QoL aspects

There were a number of different responses to the open question about the criteria for an acceptable QoL for infants born extremely preterm. The four most common answers to this question were: being able to have an independent life (32%), being like others (18%), living without medical assistance (10%) or living without a disability (8%) and 6% of respondents could not answer the question. The minimum criteria for an acceptable QoL, with multiple responses possible, included: showing happiness and emotions (94.4%), communication with others (93.6%), taking care of oneself (75.7%), completing primary school (73.0%) and earning one‘s own living (65.2%).

Irrespective of the assumed future QoL, 45.2% believed that all possible therapeutic measures should be undertaken to enable the survival of extremely preterm infants, while 43.1% did not agree, and 11.7% did not know. It was significant that fewer French-speaking than German-speaking or Italian-speaking people considered all possible measures should be undertaken. Female respondents, people with a lower education or with strong religion supported intensive care treatment regardless of QoL considerations (Table 3).

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DISCUSSION

This representative Swiss population-based study aimed to provide information about the current knowledge of lay-people on complex questions regarding EoL decisions for infants born extremely premature. This survey found distinct preferences regarding the type of decision-making and also demonstrated significant socio-cultural differences in the EoLDM process.

Our study found that the Swiss population explicitly preferred to reach consensus on an EoL decision through a shared dialogue between the healthcare team and parents. This is in contrast to a paternalistic approach where decisions are solely made by the healthcare team or by the physician. Such a collaborative approach allows healthcare staff to take into account social and familial factors at play in the decision-making process. This preference confirms the previously reported importance of informed and shared decisions in paediatrics (12) and, more specifically, in EoL decisions for infants born at the limit of viability (13,14). In cases where there were diverging views between parents and the healthcare team, people clearly favoured an approach in which the parents acted as the final decision-makers. This was consistent with other studies that considered parental authority as imperative in the final decision (12,15), although implementation of parental authority still varies extensively (16). Interestingly, very few of the Swiss people in our study said that they would rely on the expertise of an independent ethical committee with regard to EoL decisions, even in situations of dissent, while many other countries rely strongly on ethical committees to mediate in problematic decision-making issues (17).

Despite the increasing importance of parental authority in cases of disagreement, in clinical practice it can be unclear how to balance familial autonomy with the best interest of the child. An in-depth discussion on parental autonomy is beyond the scope of this paper, but it is important to contextualise surrogate

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decision-making. This notion supports the principle of respecting the patients' autonomy, which in the context of neonates refers to the parental autonomy as the legal proxy of the child. The Swiss Civil Code for the protections of adults and children, enacted in 2013, clearly promotes and re-emphasises parental authority and family autonomy when a paediatric patient is incapable of taking his or her own decisions (18). Since decision-making by proxy cannot be based on the prior wishes, views and values of the infant, it is therefore based on the best interests and assumed future QoL of the child (19). Although healthcare teams in neonatal intensive care units (NICUs) aim to provide extremely premature infants with the best QoL possible, this term can be interpreted in many ways. Our study revealed that the overall perceptions of the population seemed related to future considerations and notions such as independence. This pattern has also been identified by other surveys on physicians' assessments of QoL in which the child's predicted suffering, inability to communicate and future autonomy were given increasing importance (20,21). This implies that QoL should not only include the well-being of the infant, but also the infants' future potential for independence. In practice, best interest assessments encompass medical considerations (objective components) and include moral values (subjective components) of the various stakeholders. For example, the moral status of premature infants is such a subjective component. Studies have shown that infants born extremely preterm were treated differently from term newborn infants, children and adults (22). But the majority of lay people would apply equal criteria for initiating intensive care treatment in preterm infants and children. This signals the need for further public and ethical discussion regarding the differential treatment of extreme preterm infants and resource allocation.

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Often disagreement regarding the best approach to take is the result of different interpretations of what is best for the patient or results from prioritising interests differently (23). Parents' cultural or religious views can lead to persistent disagreement. Sometimes however, physicians are willing to withdraw or withhold life-sustaining treatment at the request of families, despite their belief that continued treatment would be in the best interest of their patient (24). These complexities need to be further discussed and empirical research should explore whether a threshold of acceptable care could bypass the problems physicians are faced with in their daily clinical practice.

The diverging treatment choices found in our study may be caused by Switzerland's distinct cultural composition, as the French, German and Italian linguistic regions all have their own cultural and religious backgrounds. For example, liberal attitudes towards withholding intensive care were more evident among the French-speaking population. The German-speaking population was more likely to see the parents as the final decision-makers when there was a disagreement, while the French- and Italian-speaking populations felt that the physician should have more authority. Countries close to Switzerland, such as France, Germany and Italy, have also shown these cultural tendencies in neonatal healthcare providers or parents with regard to ethical decisions (8,9,25). A Swiss study on survival outcomes of preterm infants also showed centre-to-centre differences, which were believed to be the result of a particular culture of NICUs (26). Interestingly, both religion and personal experience with prematurity were less influential than anticipated in our study. They were only prominent in decisions to initiate intensive care treatment despite an expected low QoL. This suggests that the attitudes of the populations assessed in this survey might reflect the views and attitudes that would also be expressed by the parents of preterm infants in our NICUs. As for religion, treatment decisions for neonates seem less related to religious values, as previously thought (27).

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These socio-cultural differences are particularly important when they influence life and death decisions in very premature infants. In a context fraught with clinical and prognostic uncertainty, different moral interpretations are bound to happen. Despite the aim of most national guidelines to set clear boundaries for appropriate care, studies in several European countries have shown that treatment decisions reflect local NICU cultures (8). The process of coming to a moral consensus in a shared approach within pluralistic and diverse societies can be a difficult yet important one (28).

Some limitations of this survey should be considered. A general limitation of a telephone interview is that it does not allow for in-depth exploration and both the questions and responses are limited in their complexity. Despite the fact that the phone interviews needed to be relatively short, an open question was asked on the minimal criteria for an acceptable QoL. Furthermore, our respondents were categorised into one of the three language areas according to their area of residence. Finally, we did not ask people's specific religious denomination – such as Protestant, Catholic or Muslim – but focused on people's strength of belief in order to assess the potential influence of religion on attitudes and treatment decisions. Methodologically, our response rate was common for population-based telephone surveys on healthcare topics using quota sampling. Our findings can, therefore, be generalised to the whole nation. Notwithstanding the survey's limitations, our nationwide representative sample adds to the limited knowledge of the societal attitudes and values on treatment and EoLDM for extremely premature infants (29).

In future research, it would be of interest to define a context where ethical trade-offs are accepted for decisions that cannot be considered medically beneficial or futile, but are somewhere in between. It is in this context where shared decision-making enables healthcare experts and parents to reflect on and reconcile with their underlying attitudes and values through continuous dialogue. Moreover, the

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dilemma of who should take the final decision when there is no consensus might disregard the underlying problem of assessing what is good care for extremely preterm infants. Meaningful support during EoL decisions requires optimal communication, which could limit the conflict and distress between the healthcare team and the family. The current understanding of morally pluralistic societies requires further discussion on the appropriateness of advancing regulation in the field of highly specialised neonatal intensive care and on the soundness of ethical arguments that underlie EoL decisions.

CONCLUSION

Our survey reveals that the majority of the Swiss population clearly favoured shared decisions as the most appropriate decision-making model when faced with EoL decisions for infants of extremely low gestational age. Socio-cultural demographics, especially the linguistic region, influenced the attitudes toward extreme prematurity and decision-making. Our findings provide valuable information that can be used to understand the societal attitudes, values and arguments put forward by the parents of extremely preterm infants being cared for in the NICU. It also gives an insight into comparisons between, and within, countries that can fuel and stimulate debate in neonatal medicine, but also on a societal, public level.

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CONFLICTS OF INTERESTS

The authors have no conflicts of interest to disclose.

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ABBREVIATIONS

EoL: End-of-Life

EoLDM: End-of-Life Decision-Making

NICU: Neonatal Intensive Care Unit

QoL: Quality of Life

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SUPPORTING INFORMATION

- Survey questionnaire

Table 1: Characteristics of respondents in the survey

Characteristic	**%**	**N**
Gender		
Male	49.7	602
Female	50.3	608
Region[a]		
German part	72.0	707
French part	24.0	303
Italian part	4.0	200
Age		
≤ 39 years	35.0	423
40-64 years	45.0	544
≥ 65 years	20.1	243
Having own children		
Yes	70.2	837
No	29.8	373

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Personal experience with prematurity		
Weak	68.2	831
Strong	31.5	375
Importance of religion		
Not important	48.9	586
Important	51.1	606
Education		
Low	7.2	99
Medium	66.1	805
High	26.6	297

Total N=1210. Percentage without missing values unless indicated.

[a] Regions are based on: the German speaking part, the French speaking part and the Italian speaking part of Switzerland. All results in % are weighted for regions; numbers of respondents (N) are unweighted.

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Table 2: Medical decision-making

	All	≤ 39 years	40-64 years	≥ 65 years	**Age**	German	French	Italian	**Region**
Who should decide about using intensive care	**N % (95 % CI)**	**N % (95 % CI)**	**N % (95 % CI)**	**N % (95 % CI)**	**p value**	**N % (95% CI)**	**N % (95% CI)**	**N % (95 % CI)**	**p value**
Physicians	47 2.9 (2.1-4.0)	10 1.9 (1.0-3.7)	22 3.3 (2.1-5.2)	15 4.1 (2.3-7.4)	0.217	18 2.5 (1.6-4.0)	8 2.6 (1.3-5.1)	21 10.5 (7.0-15.5)	**<0.001**
Health care team	49 3.2 (2.4-4.4)	13 2.6 (1.5-4.6)	25 3.7 (2.4-5.6)	11 3.3 (1.7-6.4)	0.641	14 2.0 (1.2-3.3)	19 6.3 (4.1-9.6)	16 8.0 (5.0-12.6)	**<0.001**
Parents	114 9.8 (8.2-	34 7.8 (5.6-	56 11.0 (8.7-	24 10.3 (7.1-	0.232	80 11.3 (9.2-	16 5.3 (3.3-	18 9.0 (5.8-	**0.011**

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	11.6)	10.8)	13.9)	14.8)		13.9)	8.4)	13.8)	
Parents and health care team	923 77.8 (75. 3- 80.0)	345 82.7 (78. 9- 86.0)	406 75.6 (71. 8- 79.0)	172 74.4 (68. 5- 79.5)	**0.01 0**	550 77.8 (74.6- 80.7)	241 79.5 (74.6 - 83.7)	132 66.0 (59. 2- 72.2)	**0.001**
Ethics committee	35 2.6 (1.8- 3.6)	9 1.9 (1.0- 3.7)	22 3.9 (2.5- 5.8)	4 0.8 (0.2- 3.0)	**0.02 5**	16 2.3 (1.4- 3.6)	10 3.3 (1.8- 6.0)	9 4.5 (2.4- 8.3)	0.221
Others[a]	31 2.9 (2.1- 4.0)	6 1.7 (0.8- 3.4)	11 2.2 (1.3- 3.8)	14 6.2 (3.8- 10.0)	**0.00 2**	23 3.3 (2.2- 4.8)	6 2.0 (0.9- 4.3)	2 1.0 (0.3- 3.6)	0.156
Do not know	11 0.9 (0.5- 1.6)	6 1.4 (0.7- 3.1)	2 0.4 (0.1- 1.3)	3 0.8 (0.2- 3.0)	0.20 2	6 0.8 (0.4- 1.8)	3 1.0 (0.3- 2.9)	2 1.0 (0.3- 3.6)	0.966
	All	≤ 39 years	40-64 years	≥ 65 years	**Age**	German	French	Italian	**Region**

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In case of disagreement, who should have the final say	**N % (95 % CI)**	**N % (95 % CI)**	**N % (95 % CI)**	**N % (95 % CI)**	**p value**	**N % (95% CI)**	**N % (95% CI)**	**N % (95 % CI)**	**p value**
Physicians	163 12.3 (10.6-14.3)	48 9.7 (7.2-12.9)	75 13.1 (10.5-16.1)	40 15.6 (11.6-20.7)	0.069	72 10.2 (8.2-12.6)	54 17.8 (13.9-22.5)	37 18.5 (13.7-24.5)	**<0.001**
Health care team	40 3.4 (2.5-4.6)	11 2.8 (1.6-4.9)	19 3.5 (2.2-5.4)	10 4.1 (2.2-7.4)	0.675	22 3.1 (2.1-4.7)	13 4.3 (2.5-7.2)	5 2.5 (1.1-5.7)	0.494
Parents	756 64.6 (61.9-67.3)	281 70.0 (65.4-74.1)	337 63.4 (59.3-67.4)	138 57.8 (51.5-63.8)	**0.005**	494 69.9 (66.4-73.1)	154 50.8 (45.2-56.4)	108 54.0 (47.1-60.8)	**<0.001**
Ethics committee	150 11.4 (9.7-	54 11.6 (8.9-	69 11.9 (9.5-	27 9.8 (6.7-	0.681	66 9.3 (7.4-	51 16.8 (13.0	33 16.5 (12.	**<0.001**

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	13.3)	15.0)	14.9)	14.2)		11.7)	- 21.5)	0- 22.3)	
Others[a]	36 3.2 (2.4- 4.4)	3 0.7 (0.2- 2.1)	17 3.3 (2.1- 5.2)	16 7.4 (4.7- 11.4)	**<0.0 01**	21 3.0 (2.0- 4.5)	13 4.3 (2.5- 7.2)	2 1.0 (0.3- 3.6)	0.104
Do not know	65 5.0 (3.9- 6.3)	26 5.2 (3.5- 7.7)	27 4.8 (3.3- 6.9)	12 5.3 (3.1- 8.9)	0.93 1	32 4.5 (3.2- 6.3)	18 5.9 (3.8- 9.2)	15 7.5 (4.6- 12.0)	0.227

Total N=1210. Unweighted N, weighted percentage for all and age or unweighted percentage for region, and 95% CI are shown. Groups (age groups or regions) were compared using a chi-squared test.

[a] Most commonly proposed decision-making styles were: everyone together, physician and parents, or parents, ethics committee.

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Table 3: Results of multivariate logistic regression for the question: “Do you think that for extremely preterm infants, irrespective of the assumed future quality of life, all possible therapeutic measures should be undertaken to enable their survival? (yes/no)”

	OR (95% CI)	**p**
Region		
German part	1	
French part	0.59 (0.43-0.80)	**0.001**
Italian part	1.98 (0.95-4.13)	0.067
Education		
low	2.49 (1.45-4.27)	**0.001**
intermediate	1	
high	1.02 (0.77-1.35)	0.901
Gender		
male	1	
female	1.36 (1.06-1.76)	**0.016**
Importance of Religion		
Not important	1	
Important	1.41 (1.10-1.81)	**0.008**

[a] Higher ORs indicate higher agreement with the statement.

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